

How to talk to someone with dementia about COVID-19

The world in which we live is a little different currently. People living with dementia are likely to have noticed this. Some may be thinking or asking "what is happening?", "why can't I go out?", "why has X stopped visiting?". Others with more significant cognitive difficulties may not remember everything about what is happening, but may be experiencing a feeling that things are different or that they have not seen a certain person in a long time. Those living with dementia are likely to be experiencing the same feelings of uncertainty, fear, anxiety, agitation and frustration to those not living with dementia currently, and thus it is important to ensure that we talk to people living with dementia about COVID-19 in a way that will make them feel safe and reassured.

Step 1 - Help the Person living with dementia to feel safe & reassured

- When we feel anxious or worried, this will often be communicated without us even realising. This is through our body language, tone of voice, posture and facial expression. For example we might be tense, clench our fists or jaws, and furrow our brow or tighten our lips when we are anxious.
- People living with quite advanced dementia can often be very tuned into emotions, even if they find it difficult to fully comprehend what we saying they will pick up on how we are feeling.
- This is important to hold in mind when talking to a person living with dementia about COVID-19. Take a note of how you feel when you think about COVID-19. It is important that you talk to family, friends, and/or colleagues and attend to your own wellbeing; so that when you are with someone who is living with dementia you can relax as much as possible.
- Try to keep your sense of humour, make jokes, smile, laugh and sing with the person living with dementia as much as possible as these things will communicate safety and reassurance and help them to feel more relaxed and at ease.

Step 2 – Maximise the effectiveness of your communication

- Make sure the individual is wearing hearing-aids and glasses when you are communicating with them, make eye contact and let them see your face as this will help with lip reading and providing clues to what you are saying.
- You need to break the information down into manageable, simple facts about what is happening.
- Consider using an 'easy read' COVID-19 information sheet for those with language comprehension difficulties, especially if the person living with dementia would like to read the information for themselves. The Learning Disability (LD) charity 'mencap' have produced an 'easy read' document for people living with learning disabilities, which could be used in such a situation https://www.mencap.org.uk/advice-and-support/health/coronavirus-covid-19 Please note that some language and images are LD specific.
- Consider using visual prompts to aid understanding, especially for those whose communication is more impaired. The organisation 'aphasiafriendly' have a wealth of visual images that can printed, cut out and used to discuss COVID-19: http://www.aphasiafriendly.co/covid-19-accessible-information.html
- Allow the person living with dementia additional time to understand what you are saying, and give them time to ask questions, do not rush this conversation – allocate sufficient time.

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• You may need to repeat the information you give the person living with dementia throughout the day, as their cognitive impairment may make it very difficult for them to remember this new information. Be prepared to repeat the information whenever necessary – ideally word for word.

Step 3 – Explain what the virus is

- Part of the importance of explaining what COVID-19 is, is to encourage the person living with dementia to adhere to current hand washing and social distancing guidelines. NOTE - There is a separate document with advice and recommendations on how to encourage a person living with dementia to wash their hands regularly.
- It may be helpful to explain to the person living with dementia (if they have intact verbal communication skills) that the impact of COVID-19 is very similar to a "nasty flu" and "is contagious". People living with dementia are less likely to be able to learn and retain new information, including terms such as "coronavirus", "COVID-19", "social distancing" and "self-isolation", so avoid these.
- Explain that the most common symptoms are a "dry cough" and/or a "high temperature" ("fever").

Step 4 – Explain why we have to restrict our movement presently

- As above, saying phrases such as "contagious flu" will help the person living with dementia to understand the severity of what is going on presently.
- Tell the person living with dementia that the "Government's guidance" is for "everyone to stay at home", and this is to "keep them safe". You may choose to add that "spending time in the garden or a short-walk is allowed".
- It may be helpful to say that "the Government is taking this very seriously" and "they want to protect people" so the person living with dementia feels reassured.

Step 5 – Explain why family and friends cannot visit presently

- Explain that the Government are "telling everyone to stay at home" and that "this is to keep us and our family safe, and to avoid people living becoming ill".
- Explain that this means that, whilst family may still want to visit, "the Government cannot allow this" and again repeat the phrases "the Government is taking this very seriously" and "we want to protect people living".
- Use this conversation to start to explore alternative ways for the person living with dementia to keep in touch with their relatives and friends including; phone calls, video calling or letters. NOTE -There is a separate guidance document for this.

Step 6 – Explain why we have to keep our distance presently

- Say that "the flu spreads when people are too close" so "we need to stay apart to stop it spreading".
- It may be very difficult to adhere to social distancing completely, especially if the person living with dementia lives in a care setting and/or 'walks with purpose' (formerly known as 'wandering'). Note There is a separate guidance on caring for people living with dementia who 'walk with purpose'.

Step 7 – Ensure the person living with dementia leaves the conversation feeling safe and secure and facilitate any follow-up questions

- Return to Steps 1 and 2.
- Smile and use positive statements like "we will get through this" and "this won't last forever".
- Support the person living with dementia to ask follow up questions, using the 'easy read' and visual prompts if required.
- Repeat the information –whenever necessary word for word at regular intervals.

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